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## INTEGRATIVE REVIEW OF THE LITERATURE

Crianças com necessidades especiais de saúde: impacto no cotidiano familiar

Children with special health care needs: impact on familiar daily routine

Niños con necesidades médicas especiales: impacto en la rutina diaria familiar

Marcelly Fontes Simonasse <sup>1</sup>, Juliana Rezende Montenegro Medeiros de Moraes <sup>2</sup>

### ABSTRACT

**Objetivo:** Descrever através da literatura científica o impacto que as crianças com necessidades especiais de saúde causam em suas famílias. **Método:** Revisão integrativa, realizada nas bases de dados MEDLINE, BDNF, LILACS e IBECs. Foram selecionados 67 artigos publicados entre 2003 e 2013, os quais constituíram a amostra do estudo. **Resultados:** Apontaram que esta temática tem sido investigada prioritariamente em estudos internacionais e o impacto ocorre na transmissão do diagnóstico e acarreta em repercussões financeiras sobre a saúde e no cotidiano social dos membros da família. **Conclusão:** A enfermagem deve ser facilitadora e instrumentalizar a família para o cuidado às crianças com necessidades especiais de saúde. **Descritores:** Família, Cuidadores, Crianças com deficiência, Enfermagem.

### RESUMO

**Objective:** To describe through the scientific literature, the impact that children with special health care needs cause on their families. **Method:** Integrative review, performed in MEDLINE, BDNF, LILACS e IBECs database. There were 67 articles published between 2003 and 2013 selected, which constituted the study sample. **Results:** This issue has been investigated with priority in international studies and the impact occurs in the transmission of the diagnosis and results in financial repercussions, on health and everyday social life of family members. **Conclusion:** Nursing should be facilitate and mediate the family for children's care with special health needs. **Descriptors:** Family, Caregivers, Disabled children, Nursing.

### RESUMEN

**Objetivo:** Describir a través de la literatura científica, el impacto que los niños con necesidades especiales de salud causan en sus familias. **Método:** Revisión integradora, realizada en base de datos MEDLINE, BDNF, LILACS y IBECs. Se seleccionaron 67 artículos publicados entre 2003 y 2013, los que constituyen la muestra del estudio. **Resultados:** Los resultados revelaron que este tema se ha investigado, con prioridad en estudios internacionales, y que el impacto ocurre en la transmisión del diagnóstico y resulta en consecuencias financieras, sobre la salud y sobre la vida social cotidiana de los miembros de la familia. **Conclusión:** La enfermería debe ser facilitadora e instrumentalizar la familia para cuidar a niños con necesidades especiales de salud. **Descriptores:** Familia, Cuidadores, Niños con discapacidad, Enfermería.

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## INTRODUCTION

**C**hildren with Special Health Needs (CRIANES) are those with special health conditions with continuous care demand, whether temporary or permanent, and needing health and social services besides those required by all children.<sup>1</sup>

According to a typology of care in Brazil, CRIANES were classified in five groups: development, technological, medical, modified standard and mixed demands. In the development demand, children with neuromuscular dysfunction requiring psychomotor and social rehabilitation are included. In technology demand, there are technology dependents. In the medical segment, there are the medication dependents. In modified standard demand, there are those who depend on modifications in the usual way to care themselves. At last, the mixed ones are those having one or more demands together.<sup>1-2</sup>

CRIANES care impacts the family, since requires the adoption of numerous rehabilitation measures to day-to-day activities, whose knowledge and practices cannot belong to the context of their lives.<sup>2</sup>

Sometimes, these children have complex diseases and require continuous and specialized care. It is common for some CRIANES to require prolonged hospitalization and increased care demand proportionally to the time hospitalized. At the hospital, members of the nursing team are those taking care of them, but after discharge, the family will take care of them at home.

Therefore, it is necessary that the family get technical and scientific knowledge to meet the demand of care required by CRIANES such as math concepts, disinfection, drug interactions, signs and symptoms of infection, among others. The hospital discharge planning has been described in the literature as a possibility of nursing to mediate and prepare the family to care for a child with special health needs.<sup>1,3</sup>

The discharge process must occur slowly and gradually, progressing gradually as doubts are resolved between nursing and family. In this way, it is intended to stimulate autonomy, the exchange of ideas and opinions about the care to be performed, realizing the real need and helping to reduce the impact on the family having a member with special health needs.<sup>4</sup>

Thus, the following question was created: What is the impact that a child with special health needs cause in your family? And the following objective: to describe, through scientific literature, the impact that children with special health care needs cause on their families.

## METHOD

It is an integrative literature review enabling to identify knowledge gaps, identify the need for future research, reveal central issues of the focus area, identify conceptual or theoretical references and show the art state of scientific literature on a given theme.<sup>5</sup>

This study was developed according to the following steps: theme identification and preparation of the study question; establishment of inclusion and exclusion criteria; categorization and evaluation of studies included in the integrative review; interpretation of results and synthesis of knowledge.<sup>5</sup>

The search for information in the literature occurred during April and May 2013, through MEDLINE, BDENF, LILACS and IBECs databases. The key words used were “disabled children”, “family”, “caregivers”, grouped in pairs through the Boolean operator “and”. Inclusion criteria were articles from 2003 to 2013, available in full version considering articles in Portuguese, English and Spanish and addressing the special needs of the child in the family impact. The choice of starting in 2003 is justified because it that the first article in Brazil addressing and using the naming of children with special health care needs was published, which provided grants to other studies on this topic.

Initially, 474 publications were located, 67 articles meeting the inclusion criteria and answered the question of the study. An instrument containing the following variables analyzed these articles: index descriptors, journal, year and country of publication, contexts and care situations, methodology and main contributions to Nursing.

## RESULTS AND DISCUSSION

In the 67 publications selected for this integrative review, there was an increased production of children with special health care needs over the years. In 2003, only one article was published, and in 2004, two articles were published. In 2005 there were three articles, while in 2006 and 2007 four articles were published. In 2008, there were 12 publications, followed by 2009 and 2010 with 10 publications each year. In 2012, 9 articles were published.

Based on the international MEDLINE literature data, 37 articles were located, and 28 articles in LILACS, and only one article in BDENF and IBECs. Most of the publications were international from the following countries: United States (19 items) UK (6), Canada (5), Australia (3), Netherlands (2), Taiwan, India and Spain with 1 article in each country. In



only one publication was not possible to identify the country of origin. National publications were 28 articles, demonstrating that the impact of the child with special needs on the family is still an emerging topic, being needed investment for publications in Brazil.

In the literature, children with special health care needs are those with down syndrome, developmental delay, hearing impairment, learning disabilities, behavioral disorders, chronic disease, positive HIV, dependence on technology, with cerebral palsy and limited mobility.

The organization of the material was through topics, observing similarities and differences, by the following steps: pre-analysis, material exploration and data processing.<sup>6</sup> The organization of the material created three thematic units: Impact on the discovery of special need child health, Financial impact on the family, Health and the everyday impact of the family, presented below.

### **Impact on the discovery of special need child health**

At the time of discovering the diagnosis of the special health needs of their children, parents experience frustration and shock feelings. At that time, the perfect son's dream is over. The impact of the discovery of special needs cause fear in children's loss and anxiety about the future.<sup>7</sup> For CRIANES parents, this was an unforgettable moment, being marked as a scar on family memory.<sup>8</sup>

During diagnosis transmission child special needs, family members reported problems by excessive use of technical terms by health professionals, difficult to understand their reality.<sup>9</sup> They reported experiencing an "internal battle" because they wanted to know about the diagnosis of their child, but they did not believe on the information transmitted and they wanted to seek other sources of knowledge.

### **Financial impact on the family**

Parents and families of children with special health care needs may face financial issues due to the expensive specialized care required by CRIANES.

Parents of these children reported that low financial income associated with spending on specialized medicines and treatments generated anxiety in the family. It was shown that the financial impact was greater in families where at least one family member had to stop working to take care of CRIANES at home.<sup>10-1</sup>

CRIANES family members are also more likely to work part-time or be unemployed when compared with others. They seek to work with flexible hours or part-time, to combine work with care routine of children, because many families cannot afford to pay someone to assist their children. Thus, the mother will be the main caregiver of CRIANES. This caregiver involved with this heavy care routine is prevented from working and thus to contribute to the financial costs of their home.<sup>11</sup>

Families express the importance of having time to work and report that having a job helps to get a higher income, having the opportunity to spend more money to meet the needs of their children.<sup>11-2</sup>

### Health and the everyday impact of the family

The articles selected for this integrative review showed that CRIANES parents are focused on their child and ignore their basic needs and their health, resulting in terrible levels of personal well-being and a deficit in self-care.<sup>13-4</sup>

A study in India with 100 parents of children with special health care needs showed an impact on the health of these caregivers, where 71% were affected in their physical health and 58% had physical diseases. Of these parents, 56% had mental health problems related to loss or altered sleep and loss of appetite. The loss of sleep was related to night care demanded by CRIANES. Therefore, the sleep is regulated by the needs of their child.<sup>13-5</sup>

A study with 103 mothers of technology-dependent children showed that they are at high risk for clinical depression who 40% of them had experienced depressive symptoms. However, only 19% sought psychological help. The psychological distress has close relationship with low family socioeconomic status.<sup>16</sup>

The everyday of families with children with special needs is changes, when mother's routine is the most changed due to the greater amount of time spent in care, with overload on this caregiver. Mothers sacrifice their personal, family and social life to care for their children. Eventually, fathers help in direct care to CRIANES, but they are usually found in the literature as the financial provider.<sup>14-6</sup>

When the child is born comes into the world with a place already marked by desire and on parent's imaginary, they symbolically arrive. However, when the family discovers the special health needs in their child, they experience feelings of anxiety, internal conflicts, impotence, grief, and the need to adapt to the new reality. The moment of discovery of the diagnosis of special health need is experienced intensely by the family and can cause disruption, instability and leaving a scar in memory of its members.<sup>13-17</sup>

Feelings such as difficulty of acceptance, denial and rejection of the diagnosis of special health needs, together with feelings of uncertainty, helplessness, anger, grief, shock, shame and momentary loss of cultural and psychological references are also present in CRIANES families.<sup>7,16</sup> For mothers, the most prevalent feeling was to blame themselves for the child special needs, especially if it is congenital.

Parents express difficulty of knowledge about the diagnosis of their child, being important to receive support, clarification and reception of health professionals, especially nurses. They should use the meeting with the family to work as educators, respecting the family knowledge and establishing a sensitive listening.<sup>9,16</sup>

It is recommended that when revealing diagnosis of the special needs health, it occurs with the whole family together in private area and preferably with the presence of the child on the lap of one of the members. After this time, the family should remain in the place, along with the health professional to reflect about what was informed,<sup>9</sup> because the way information is given about the child's diagnosis will reduce the risk of conflicts and facilitates understanding and care by the family.

Many families sought other professionals, besides the one revealing the diagnosis of special health needs to solve the doubts and minimize their fears and anxieties. In this sense, nurses and other health professionals are essential to give trust and security for

parents in caring for their children, then overcoming the difficulties and providing humane care.<sup>18</sup> There is an increased impact of special needs health in family life when parents have difficulties in finding information and services for their child. For mothers, lack of information, psychological support and lack of knowledge about the special needs make them to not know guiding the necessary care, interfering in decision-making about how to take better care of the child.<sup>3,10-9</sup>

Some children with special health needs have high demand for care ensure their lives and in most families this care is developed by the mothers, the main caregivers. Mothers of CRIANES have overload in their daily activities by accumulating activities such as the home, the family, CRIANES and in some cases, they are even the financial provider. The high demand of care by the CRIANES reduces the opportunity of mothers and family participate in social activities, leisure, and also in their home and maintenance of new friendships. On the other hand, the few moments of leisure and recreation were classified as moments of happiness and pleasure by the whole family.<sup>10,12-4</sup>

The impact of special need child health is noticed in families suffering changes in routine, leisure and interaction among its members.<sup>13</sup> Some families also suffered geographical changes by going to other city searching of better treatment for their children.<sup>12</sup>

Due to the overestimation of the severity of their children needs, parents have terrible levels of personal welfare.<sup>10</sup>

To take care of their children, parents seek support in three social groups. The first group has the family members, including friends and neighbors; the second has the health professionals who are involved in the childcare; and the third one is the religion. In the social network of CRIANES families, religious institutions are supportive. The religion helps mothers in the routine reorganization process in the care of the family and the CRIANES.<sup>1</sup>

The care required by CRIANES cause financial impact on the family due to the cost of medications, transportation to health services, spending on inputs for care, such as: gloves, suction catheter, diaper, syringes, gauze, etc., special food, technological devices (respirators, hearing devices) and specialized professionals (physiotherapists, nurses, doctors, speech therapists).

In a study conducted in Slovenia with 20 families of CRIANES, there were more than 90% do not see the possibility of improvement in the future of their financial situation and said they were not satisfied with it. With this, all the families of children with special needs deserve financial aid because the assistance for necessary care to their child is considered expensive.<sup>12-4,20</sup>

In Brazil, a way to help these costs would be the government's investment in financial aid to families of children with special health needs. Currently, the Brazilian government provides the Benefit of Continuous Cash (BPC) for families of children with proven inability medical diagnosis. To get this beneficial, it is necessary that the per capita family income does not exceed  $\frac{1}{4}$  of the minimum wage. However, many families are still unaware of the BPC and others have difficulty to receive it.<sup>1,14-9</sup>

## CONCLUSION

The special need health of the child impacts in the family when diagnosis is transmitted and generates financial impact on the health and everyday lives of its members. The family has difficulty to communicate with health professionals, including nurses, suffering social isolation and not finding support in public policies and programs in Brazil. They seek support from other family members, friends and neighbors, health professionals and religion to meet the demand of special care required by CRIANES.

Therefore, nursing should be a facilitator in the preparation of families and children in domestic care, mediating and contributing to the empowerment of the family, and stimulating the structuring of support networks. Thus, the nursing acts as an educator and family supportive, helping to reduce the impact on the family for CRIANES with special needs.

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